

382* Comparative study of three health related quality of life instruments in cystic fibrosis patients

M. Cebrián¹, A. Solé¹, E. Ansótegui¹, A. Pastor¹, J. Pastor², S. Peiró³, M. Peña¹.
¹University Hospital La Fe, Lung Transplant and Cystic Fibrosis Unit, Valencia, Spain; ²University Hospital La Fe, Thoracic Surgery Service, Valencia, Spain; ³Centro Superior de Investigación en Salud Pública, Área de Investigación en Servicios de Salud, Valencia, Spain

Objective: To compare a generic instrument and two disease-specific instruments to measure health related quality of life (HRQoL) in patients with CF ≥ 14 years old. We focussed on the discriminative properties of the questionnaires, and correlated their domains between them, and with demographic and clinical variables. Our aim was to evaluate which questionnaire is more suitable to measure HRQoL in CF patients.

Methods: The Cystic Fibrosis Questionnaire-Revised (CFQ-R), the St. George's Respiratory Questionnaire (SGRQ), and the Short form 36 health survey (SF-36) were simultaneously self-administered in a cross-sectional study with 65 CF patients. Internal consistency (Cronbach's alpha), and convergent and construct validity (common factor analysis, correlation patterns) were calculated, as well as external validity (correlations of each questionnaire with demographic and clinical variables, such as spirometry values, pulmonary exacerbation, intravenous treatment, diabetes, pancreatic insufficiency, etc.).

Results: Similar reliability, but different validity of the questionnaires was shown when measuring HRQoL in CF. Significant correlations ($r \geq 0.60$, $p < 0.05$) were found between most of the domains in all questionnaires: physical functioning, role and social limitations, vitality, and emotional status. The SGRQ and CFQ-R showed better discriminative properties in the symptoms domain than the SF-36, plus, the CFQ-R showed a better differentiation capacity of the levels of disease severity.

Conclusion: Although the three questionnaires have proven their validity to measure HRQoL in CF, the CFQ-R appears to be the most specific, although the symptoms scale could be improved.

383* The effect of transmissible *Pseudomonas aeruginosa* strain infection on the quality of life of adult CF patients

A. Ashish¹, J. McShane¹, H. Tan¹, D. Nazareth¹, T. Jordan¹, M. Ledson¹, M. Walshaw¹. ¹Liverpool Heart and Chest Hospital, Liverpool, United Kingdom

Although adult CF patients who harbour epidemic *Pseudomonas aeruginosa* (Psa) strains have a more rapid decline in physical markers of diseases severity and increased mortality compared to other CF patients, it is not known if they also have a poorer health related quality of life (HRQoL). To study this, we looked at HRQoL in 136 CF patients (75 with transmissible Psa [median age 26 years {IQ range 26–31}, 38 females]; 42 with unique Psa strains [median age 22 years {IQ range 20–28}, 16 females], and 19 without Psa infection [median age 21 years {IQ range 19–29}, 9 females]) in a period of clinical stability. All completed the CFQ-UK (adult version, 12 dimensions of QOL analysed) prior to seeing any health professional in the clinic. Those with B cepacia and atypical CF were excluded. Kruksal-Wallis and Mann-Whitney's U tests were used to analyse the data.

Those with transmissible Psa infection had worse physical function, a higher treatment burden, and worse respiratory symptoms than those with unique Psa strains (all $p = 0.02$), and worse physical function ($p = 0.06$), body image ($p = 0.001$), respiratory symptoms ($p = 0.0007$) and a higher treatment burden ($p = 0.018$) than those without any form of Psa infection.

Thus, chronic infection with transmissible Psa strains in adult CF patients results in more chest related symptoms, poorer physical functioning, and a higher perceived treatment burden compared to other CF patients, and this is most pronounced compared to those without any Psa infection. Transmissible Psa strains not only affect the overall prognosis in CF, but also result in a poorer quality of life: this reinforces the need to prevent such infections in CF community.

384* Health care preferences and satisfaction in adolescents with CF

G. Ullrich¹, K. Stahl². ¹Clinical Research, Schwerin, Germany; ²Picker Institute Germany, Hamburg, Germany

Satisfaction with health care and physician behaviour in particular is one of the determinants of adherence. We aimed to gather information about so far unknown preferences of CF adolescents and their satisfaction with health care. This study is part of a broader pilot study on satisfaction with health care in adolescents, adults and parents of CF minors (conducted in 4 large CF centres).

Methods: We used the generic questionnaire of health care preferences of chronically ill adolescents (Britto et al. 2001) and applied the set of 82 items with a twofold instruction: The 1st asked about the adolescent's preferences, the 2nd asked about the perception of the actual health care. Satisfaction was considered a function of preferences being met. To prevent questionnaire fatigue, we offered to skip the second instruction.

Sample: Adolescents aged 12 to 17 were asked to participate in this anonymous investigation.

Results: 59 out of 76 eligible patients (78%) returned the questionnaire, which is comparable to the other groups from the larger study (CF adults: 70%; CF parents: 83%). None of the adolescents skipped the second instruction. Patients' preferences were largely similar to those assessed by Britto et al. (2001), i.e. doctor-patient-relationship was considered most important. An age appropriate physical environment was less relevant. There was a high concordance between preferences and actual health care (i.e. satisfaction), however this was less so regarding items focussing on the doctor-patient-communication.

Conclusion: The high response rate and the completion of both instructions indicate a good fit of the questionnaire to the adolescents' preferences and needs.

385 Conceptual approach of an educational evaluation system for patients: perception of utility by patients and caregivers

V. David¹, C. Berville¹, M. Kerbrat¹, P. Douaud¹, C. Marchand², J. Iguenane², R. Gagnayre². ¹Centre de Référence Mucoviscidose du CHU de Nantes, Nantes, France; ²University Paris 13, Laboratory of Pedagogy of Health, Paris, France

Introduction: In the perspective of therapeutic education for patients with CF, the CFR centre of Nantes participated in the validation of an educational evaluation system elaborated by a Laboratory of pedagogic health. The objective was to assess patient's evolution in different types of competences.

Methods: The system was tested with 40 patients aged 16 years old or more. Each patient tested the system three times, every three month. The system included: a knowledge questionnaire with certainty degrees, self-evaluation about strategies to solve a situation/problem, adaptation and anticipation for a new situation, self esteem, effectiveness about treatments, life plan, control of the gesture or the technique, effectiveness of one gesture or the technique. The patient and the caregiver have to agree together on the rating of each activity, then plotted on an evolution tool, represented by a star. A questionnaire was administered to the patients and the caregivers at the end of the study.

Results and Conclusion: After 144 evaluations, 48 patients and 7 caregivers completed a questionnaire. 95.7% of patients have enjoyed their participation. The main benefits perceived by patients are: involving in evaluation and resulting decisions, awareness of their knowledge and development of their skills. For the caregivers, it allows to structure activity evaluation, to better understand and make decisions about health care choices and the learning needs of the patient. The benefits perceived by patients and caregivers tend to show the interest of such an educational evaluation system in particular on the implications of shared decision.